



## Issue 5

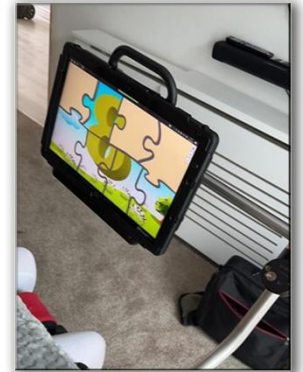
### A small sample of our achievements throughout 2023, which has been our busiest year ever.

We continue to work closely with Social workers, Hospital welfare, Hospital Nurses and Families directly.

Please read on for more information

### Eyegaze System and Software

An eyegaze device is essentially a traditional tablet, however instead of using your hands or a mouse to navigate the screen, your eyes do the scrolling. Thanks to an inbuilt light sensor, the tablet monitors reflections from the pupils, tracking eye movements and converting them into mouse movements and co-ordinated commands. By looking anywhere on the screen, the user's eye controls the cursor, while blinking performs a click. The accessibility of eye gaze technology is much the same as any off the shelf computer, so it can accommodate for more sophisticated demands such as right, double, and left clicks, which gives the user much more freedom. When paired with appropriate software, the synthesised voice will iterate words and sentences based on the input of the user. Akin to grid pads and Light writers, eye gaze machines also have internet and Bluetooth connectivity, allowing for the sending and receiving of emails, text messages and controlling the surrounding environment.



The total cost for an Eyegaze system is £10,000. This includes all necessary programmes to take a child into adulthood. We have purchase 2 so far this year, one for a young child aged 14, who has cerebral palsy and epilepsy. Although she cannot walk, talk or sit correctly she is a very clever and intelligent young girl. She loves to swim, go shopping and technology. The school she attends allow her the use of an Eyegaze system to assist her education. Having this will also promote her independence as she is currently very reliant on adult support for her current communication aid.

### Computers and workstations for multiple children



We have continued to supply computers, printers, and workstations for numerous children to help catch up or further their education. What is the importance of education?

It helps children become better citizens, get better-paid jobs, and shows the difference between good and bad. Education shows us the importance of hard work and, at the same time, helps us grow and develop. Therefore, we can shape a better society to live in by knowing and respecting rights, laws, and regulations. Education can also lead to more accurate health beliefs and knowledge, lead to better lifestyle choices and to develop skills and greater self-advocacy.

Education also helps to improves skills such as literacy, develops effective habits, and may improve cognitive ability.



### Heathfield Red Posture Chair for James



James has myotonic dystrophy which he has had from birth. He has a chair at school which has really helped him with his posture and to sit in the correct position. It has adjustable chair arms and legs which make him so much more Independent when transferring from the chair to standing and vice versa.

The Heathfield chair will have a lasting impact on James's life and will also alleviate his muscles.



## SEN Days

This year we have seen an increase in the number of families participating in our SEN days. Sadly, at present, we can only hold these in and around Boston, however, we are hoping to increase our catchment in 2024 and beyond, the day is fun for the children and parents alike. The sessions allow everybody with similar circumstances and experiences the opportunity to discuss the needs of each other and offer help and support to each other. The SEN days are creating a fantastic network of like-minded people.



## Assistance Dogs

Teddy [pictured] is one of two Autism assistance dogs we have purchased this year, being a goldendoodle, he is a hypoallergenic type of breed which means he doesn't or hardly sheds his coat. He is being trained for Oakley, who's conditions are Severe eczema, Ichthyosis vulgaris, Severe sensory processing disorder, Atopic keratitis, Autism spectrum disorder, Severe anxiety, separation anxiety, has difficulty maintaining postures and limited physical endurance, difficulty with some fine motor skills, social communication difficulties and Severe difficulties sleeping. This is why a hypoallergenic type of breed is important. Having Teddy will improve the lives of the whole family, but in particular, Oakley's.



## Sensory Rooms, Sensory Safe Beds



This year we have completed an amazing 5 sensory rooms 3 of which also contained sensory/safe beds.

We have provided sensory equipment and sensory toys for over 40 children.

We believe that having a safe place for children to sleep and play is very important to a child's welfare.

We regularly receive requests from families desperate for a safe bed due to their child banging their head or falling out of a bed and therefore hurting themselves.

A safe bed is heavily padded and therefore it will protect the child.



## We have also provided many children with electric & manual Wheelchairs, Strollers and Medical Equipment



## We continue to support and provide Hydrotherapy & Physiotherapy sessions for multiple children



## Providing Respite and Holidays

This season, we will see our holiday homes provide respite/holidays for over 180 families!!

A short break away is often key for the survival of family relationships during the roller-coaster ride of childhood illnesses. For this reason, we feel that it is very important to give families the quality time together that they so desperately need, away from hospitals, doctors, and treatment.

1 of our 3 holiday homes is situated at Butlins Caravan Village, Skegness and 2 are situated at Haven's Golden Sands Holiday Park, Mablethorpe.

We are now able provide respite and holidays for between 170 and 190 deserving families each year.

The Parks have amenities to suit all ages whether rain or shine, they are wheelchair friendly throughout and are within close proximity to all the amenities and the beach.

All our holiday homes are adapted for the disabled and well equipped throughout, each having the following:

Wheelchair access ramp, Hoist in Main Bedroom, Adapted Wet Room, Lowered work surfaces, Double and Single bed in main bedroom, lowered light switches and sockets, Wheelchair access to each room, Extra wide sliding doors, fully accessible throughout, Central Heating and Double glazing.

**The Total annual running costs for our 3 Holiday homes for 2023 is £28,029.30**



## Further achievements throughout 2023:

**Provided a large selection of disability equipment, items such as lifting hoists, walking aids and travel systems.**

**Supplied Multiple Beds, Cots, Mattresses, and Bedding, White goods, an Oven, Carpets and Flooring, Equipment Storage sheds, Sensory toys, Hydrotherapy and Physiotherapy.**

**Supported and continue to support a horticultural project in Devon. We have continued to cover hospital transport and accommodation costs, continued to provide food parcels, and aided with utility bills in addition to telephone help, advice, and support.**

## A small selection of our current projects

### A Jiraffe Jenx Standz Standing Frame for A 6 year old boy

Alex was diagnosed at birth with nonketotic hyperglycinaemia (NKH). dislocated hips, infrequent bladder emptying (which causes pain), severe development delay, he has frequent multiple seizures, is gastrostomy fed, and is nonverbal.

He has a significant metabolic condition with a very limited movement and would greatly benefit from a standing frame to ensure that he retains the best possible position he can for his legs and hips to maintain some semblance of strength.

The Standz:

Abduction stander complete with all accessories. is a versatile standing system offering Prone or Supine standing that accommodates either abducted or neutral leg positioning for children. Standz can accommodate children with a range of postural requirements.

**The total price including accessories is £3,612**



*NKH is a disorder characterized by abnormally high levels of a molecule called glycine in the body (hyperglycinemia). The excess glycine builds up in tissues and organs, particularly the brain. Affected individuals have serious neurological problems. (NKH) is a genetic condition that can lead to serious neurological problems, coma, and death. "Hyperglycinemia" refers to abnormally high levels of a molecule, glycine. The word "nonketotic" distinguishes NKH from certain other health conditions that can cause increased glycine. The condition is also sometimes called "glycine encephalopathy," meaning a disease that damages the brain.*

## Top End Eliminator NRG Carbon Hybrid Racing Chair for a young child named Toby



We are seeking £9,291.50 towards supplying a Top End Eliminator NRG Carbon Hybrid Racing Chair for a young child named Toby aged 13 who has Functional Neurological Disorder (FND), Spinal Cord Injury (SPI) and still has 30% Cancer wrapped around his spinal cord. In June of 2021, Toby's world was turned upside down. Initially complaining of backache, he was referred for physiotherapy. Toby loved sports, especially rugby, playing in his local Under 11s team, so aches and bruises were nothing unusual.

However, a couple of weeks later, Toby struggled to stand, his condition rapidly deteriorated and within a short time, had completely lost control of his lower body and was rushed to Great Western Hospital in Swindon. An emergency MRI scan revealed a previously undetected tumour, which had developed in and around Toby's spinal cord and spanned two-thirds the length of his spine, he was immediately blue-lighted to the John Radcliffe Hospital for specialist attention where surgeons took the decision to perform emergency surgery.

This involved removing sections of vertebrae from Toby's spine to relieve the pressure on the spinal cord, after the gruelling 8-hour operation, they removed 70% of the tumour but felt that the remaining 30% was too risky to touch. After the operation, Toby spent 3 months' rehabilitation in hospital and has defied the original long-term prognosis that he would never regain the use of his legs. Toby's determination and mental courage combined with excellent care from his family and hospital staff, saw him gradually rebuild his strength, everyone in his neuro, rehab teams and family were absolutely blown away when he took his first steps. All concerned were incredibly moved with his positive mental attitude and mind set.

As soon as Toby arrived back home, he immediately started searching to see what sports were best suited to him. As he had previously played rugby the obvious choice to start with was wheelchair rugby, he then joined his local club which folded and now plays competitively for the Solent Sharks and is also in the team GB youth development program.

He then received a zoom call from Nathan Maguire, the world-renowned British wheelchair racer who has won multiple medals at both the 2018 and 2021 World Para Athletic, European Championships, and has also won 400 mixed class races at multiple British Athletics Champion ships. Whilst chatting, Nathan showed Toby some of his gold medals, that zoom call truly changed Toby's life as it drove him to take up the sport himself, he has since raced and competed in regular local competitions and now holds 2 junior gold medals for Wiltshire in both the 100m and 200m wheelchair races.

Toby's main goal is to compete at the next Commonwealth games.

He is trained by a professional Para coach who is aiming to take Toby to the next level.

Toby is currently using a club owned race training wheelchair constructed from metal which because of its weight and design affects his ability to reach his potential top speeds.

Toby's long-term aspiration is to become part of the GB Paralympian Team and participate in racing wheelchair events around the world, to help him achieve his aims we have agreed to help fund a Top Eliminator NRG Racing Wheelchair which is Top End's fastest, lightest, stiffest, and most responsive ride available designed for elite racers seeking to be at the top of the podium.

This chair is designed to take Toby's career into adulthood and the only thing that will need changing would be the seating as he grows.

## Multiple Acheeva Learning Stations

The Acheeva Learning Station is designed to help children with special needs learn how to move independently.

These include those with cerebral palsy, autism, Down's syndrome, multiple sclerosis, spinal cord injuries and many other conditions.

Acheeva are height adjustable mobile therapy beds that help children maintain a functional position throughout the day.

It provides support for those who cannot move around easily due to illness, injury, surgery, or disability.

In today's world, there are many factors influencing how people learn, for example, the ability to sit up straight, whether you are able to move around freely, or interact with others. If you have a child who requires extra care or assistance, it can be difficult to find schools that provide the best possible opportunities, however, we believe that every child deserves access to education regardless of their circumstances.

The Acheeva Learning Station can be used in educational environments – such as Schools and Colleges.

It enables children with complex needs to be comfortable, and easily integrated into classroom activities.

This device allows children to lie flat, supporting their spine and head while maintaining good balance and posture.

They can then engage in activities such as reading, writing, drawing, painting, playing games or listening to music.

**The total cost for an Acheeva Learning Station is £8,000.**



**THE PROJECTS ABOVE ARE ONLY A SMALL PROPORTION OF THE TOTAL NUMBER OF APPLICATIONS THAT WE ARE WORKING ON**

**THE LIST GROWS, EACH AND EVERY WEEK**

**We appreciate we can't help everybody, but with your help, we can help so many more.  
Thank you for taking the time and interest to read through our latest newsletter.**

You can find more information regarding all our projects on our website: [makethemsmile.org.uk](http://makethemsmile.org.uk)  
If you feel you can help or would like to donate to any of our projects, you can do this by bank transfer direct to our bank account or at any Lloyds Bank, our details are

**Sort Code 77-72-25 - Account number 40723568**

or alternatively, by visiting our website: [www.makethemsmile.org.uk](http://www.makethemsmile.org.uk) and click on the **donate** button.

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